

# **THE LEGISLATIVE BLUE RIBBON COMMISSION ON AUTISM**

## **EARLY IDENTIFICATION OF AUTISM SPECTRUM DISORDERS**

### **Defining Autism Spectrum Disorders**

Autism is a complex neurobiological disorder of development that lasts throughout a person's lifetime. Because persons with autism exhibit different symptoms or behaviors, ranging from mild to serious, autism is a "spectrum" disorder, or a group of disorders with a range of similar features. Autism spectrum disorders (ASD) include autistic disorder (or classic autism); Asperger syndrome; and Pervasive Developmental Disorder Not Otherwise Specified (or atypical autism). Pervasive developmental disorders (PDDs) encompass a broader group of conditions, including ASD, childhood disintegrative disorder, and Rett syndrome.<sup>1</sup>

### **Importance of Early Identification**

Early identification of ASD is critical for children to receive appropriate interventions and support services as early in life as possible. Research indicates that early intervention can improve children's developmental outcomes, including improved language, cognitive, social, and motor skills.<sup>2</sup>

### **Age and Symptoms for Diagnosis**

ASD can often be reliably diagnosed in children by the age of two or three years, and the symptoms of ASD may be observable in children by 18 months or even one year according to some studies.<sup>3</sup> Children with ASD do not follow the typical patterns of child development; rather ASD is marked by the absence of ordinary skills that would be expected according to the major developmental milestones. Research has identified a number of developmental "red flags" that can indicate ASD in young children: poor eye contact, reduced responsive smiling, diminished babbling, reduced social responsivity, and difficulty with language development, play, and initiating or sustaining social interaction.<sup>4</sup>

Despite the progress made in early detection techniques, many children with ASD are not diagnosed until they reach school age. It is estimated that less than 50 percent of children are diagnosed before kindergarten.<sup>5</sup> A recent study of children enrolled in the federal health insurance program Medicaid found that the average age of diagnosis for white children with ASD is six years old, while African American children tend to receive a diagnosis about two years later.<sup>6</sup> Recent national and California-specific surveys of parents report that Hispanic children are less likely to have an ASD diagnosis.<sup>7</sup> These findings indicate that there may be differences in symptom recognition and diagnosis across racial and ethnic groups, as well as disparities in access to information about ASD and continuity of health care. Another recent study found that children with ASD may experience a 13-month delay between initial evaluation and actual diagnosis.<sup>8</sup> In this study of children in metropolitan Atlanta, children were initially evaluated at an average age of four years but were not diagnosed with ASD until an average age

of about five years. Reasons for the delay were not explored. Delayed identification means that early opportunities for treatment are missed.

### **The Role of Parents, Pediatricians, and Others Working with Children**

Parents are usually the first to notice unusual behaviors in their child. Research shows that parents are usually correct in their concerns about their child's development.<sup>9</sup> Child care providers and others interacting with young children on a regular basis are also in a position to identify problems, so it is important that they also be aware of the symptoms. Surveys show that parents want information and guidance from their health care provider about their child's development.<sup>10</sup>

Primary care pediatricians play an important role in the detection and management of ASD in children. The American Academy of Pediatrics (AAP) and the American Academy of Neurology have published policy statements to promote early identification of developmental disorders, including ASD.<sup>11</sup> Despite collaborative efforts by the federal government, physicians' groups, and autism-focused information and advocacy organizations to promote greater awareness of ASD, gaps remain in public and pediatrician knowledge and detection efforts for ASD.<sup>12</sup>

### **Developmental Screenings and Comprehensive Evaluations**

There are currently no medical diagnostic tests for ASD. Instead, pediatricians and clinical specialists must rely on parental report, judgment, and the ability to recognize the behavioral characteristics that define ASD.<sup>13</sup> By definition, ASD span a range of developmental disorders, with symptoms ranging from the mild to the severe.<sup>14</sup> Detecting ASD in young children with mild symptoms can be challenging and generate concerns about labeling or incorrectly diagnosing a child. Children with some forms of ASD, such as Asperger's syndrome, may not be identified at a young age and instead receive a diagnosis at a later age when their symptoms become more severe. In those cases, there are missed opportunities for early interventions.

There are two steps in the process for detecting ASD: (1) a developmental screening that briefly assesses who should be assessed more thoroughly and (2) a comprehensive diagnostic evaluation, often conducted by specialists or a multidisciplinary team, to rule ASD in or out.<sup>15</sup> Several ASD screening tests exist; however, these tools do not identify all children with ASD, and they continue to be refined to improve their accuracy and implementation, including their sensitivity for use among different racial and ethnic groups.<sup>16</sup> The AAP recommends that developmental screenings "be incorporated at every well-child visit" and "screening tests should be administered regularly at the 9-, 18-, and 30-month visits" (or alternatively during the 24-month visit).<sup>17</sup> However, surveys of pediatricians show that few pediatricians use effective means to screen patients for developmental problems, and many pediatricians report being inadequately trained in developmental assessments and lacking time and reimbursement to conduct these assessments.<sup>18</sup> A recent study found that 82 percent of pediatricians surveyed in Maryland and Delaware said they regularly screened for developmental delays and only eight percent said they regularly screened for ASD.<sup>19</sup> Lack of familiarity with the screening tools for

ASD was the reason cited by nearly two-thirds of those who reported not screening for ASD, and nearly half said they referred the child to a clinical specialist instead.

## **Best Practice Guidelines**

*ASD Best Practice Guidelines for Screening, Diagnosis, and Assessment*, a 2002 publication by the California Department of Developmental Services (DDS), was developed by experts in the field of ASD to provide recommendations for professionals, service coordinators and providers, and parents to use in the early identification of children with ASD in California. DDS is the state agency responsible for the oversight of developmental services programs for Californians with developmental disabilities. DDS conducted an initiative to promote the use of these guidelines among entities that serve persons with ASD. Since use of the guidelines is not mandated by the state, it is not clear how widely these guidelines are used statewide.

## **Identifying Gaps in State Policy**

There may be gaps in state policy related to the early identification of children with ASD. Consideration may be given to the following issues:

- Better information about ASD and the symptoms given to the public, parents, health care providers, child care and early childhood education providers, and others that interact with children;
- Best practices in educating and training health care providers and other providers that interact with children on the availability and proper use of appropriate developmental screening tools that screen children for ASD;
- Barriers to the use of developmental screening tools such as reimbursement for health care providers' costs and other possible impediments;
- Benefits of having linkages between health care providers and other entities providing early intervention, child care, and educational services for children with ASD;
- Differences in the recognition and diagnosis of symptoms of ASD for children from different racial and ethnic groups; and
- Consistent, statewide implementation of the best practice guidelines for screening, diagnosis, and assessment of ASD.

## Endnotes

- <sup>1</sup> National Institute of Child Health and Human Development (NICHD), *Autism Overview: What We Know*, U.S. Department of Health and Human Services, National Institutes of Health (NIH), publication no. NIH 05-5592, Bethesda, Maryland, May 2005, available at [www.nichd.nih.gov](http://www.nichd.nih.gov).
- <sup>2</sup> Centers for Disease Control and Prevention (CDC), "Can Developmental Screening Provide Early Detection?" October 29, 2004; and National Research Council, *Educating Children with Autism*, Washington, DC: National Academy Press, 2001.
- <sup>3</sup> Stock, M., *Autism Spectrum Disorders (Pervasive Developmental Disorders)*, National Institute of Mental Health (NIMH), publication no. NIH-04-5511, Bethesda, Maryland, 2004, available at <http://www.nimh.nih.gov/publicat/autism.cfm>; and NICHD, *Autism Overview: What We Know*.
- <sup>4</sup> Kennedy Krieger Institute, "New Study Shows Autism-Related Developmental 'Red Flags' Identifiable At Age Two In Children With Autism Spectrum Disorders," press release, June 1, 2006, available at [www.kennedykrieger.org/](http://www.kennedykrieger.org/).
- <sup>5</sup> Stock, *Autism Spectrum Disorders (Pervasive Developmental Disorders)*; and CDC, "Can Developmental Screening Provide Early Detection?"
- <sup>6</sup> McCook, A., "Autism Diagnosis Comes Later for Blacks Than Whites," Reuters News Center, November 22, 2002.
- <sup>7</sup> University of California at Los Angeles, Center for Health Policy Research, "Health Policy Fact Sheet: Autism Rates Rising in California," September 2006, available at <http://www.healthpolicy.ucla.edu>; and CDC, "Fact Sheet, MMWR – 'Parental Report of Diagnosed Autism in Children Aged 4-17 Years, United States, 2003-04'," May 4, 2006.
- <sup>8</sup> CDC, "Thirteen Month Delay Between Evaluation and Autism Diagnosis in Children," press release, May 10, 2006, available at <http://www.cdc.gov/od/oc/media/pressrel/r060510.htm>.
- <sup>9</sup> American Academy of Pediatrics (AAP), "The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children," *Pediatrics*, May 2001, 107(5): 1221-1226, available at <http://pediatrics.aappublications.org/cgi/content/full/107/5/e85>.
- <sup>10</sup> CDC, "Can Developmental Screening Provide Early Detection?"
- <sup>11</sup> American Academy of Neurology and the Child Neurology Society, "Practice Parameter: Screening and Diagnosis of Autism," *Neurology*, 2000, 55: 468-479; AAP, "Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening," *Pediatrics*, July 2006, 118(1): 405-420; and AAP, "The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children."
- <sup>12</sup> CDC, "CDC Launches 'Learn the Signs. Act Early.' Campaign," press release, February 22, 2005.
- <sup>13</sup> AAP, "The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children."
- <sup>14</sup> *The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*, published by the American Psychiatric Association, includes the definition of and criteria for diagnosing autism spectrum disorders.
- <sup>15</sup> Stock, *Autism Spectrum Disorders (Pervasive Developmental Disorders)*, NIMH.
- <sup>16</sup> Medscape, "The Diagnosis of Autism: An Expert Interview With Catherine Lord, PhD," *Medscape Psychiatry and Mental Health*, 10(2), July 11, 2005; and Autism Expert Working Group, "Autism Spectrum Disorders (ASD) Roadmap, Presented to Interagency Autism Coordinating Committee," May 16, 2005.
- <sup>17</sup> AAP, "Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening."
- <sup>18</sup> AAP, "Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening,"; and CDC, "Barriers to Developmental Screening According to Pediatricians, Results from AAP Surveys of Pediatricians," undated document.
- <sup>19</sup> Johns Hopkins Children's Center, "Pediatricians Fail to Screen for Autism, Hopkins Study Finds," press release, May 9, 2006, available at <http://www.hopkinschildrens.org/pages/news/press>.